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SICKLE CELL ANEMIA: A Preliminary Survey

Lenwood G. Davis
Department of Black Studies
Ohio State University

Mrs. Mary Vance, Editor
Post Office Box 229
Monticello, Illinois 61856

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SICKLE CELL ANEMIA: A PRELIMINARY SURVEY

compiled by

Lenwood G. Davis
Department of Black Studies
Ohio State University
Columbus, Ohio

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INTRODUCTION

Most people believe that sickle cell anemia is a new phenomenon that affects only Blacks in America. It has been well documented, however, that sickle cell originated in Africa centuries ago and, moreover, that the sickling developed as a functional adaption to malaria. It has also been proven that whites from Asia Minor carried the trait and disease to Africa many centuries ago.

As Doris Y. Wilkinson has pointed out while the evolution of sickle cell and its compatability with varying types of malaria will be disputed for some time, as will the methods of diagnosis and treatment, it is known that even though a disproportionate number of those of African descent have sickle cell, the distribution of the trait and the disease is not restricted to African countries. The sickling phenomenon has been discovered in Greece, Central America, Indonesia, India. Turkey, and European countries. It has been found not only among those of predominatly African heritage but among Mexicans, Jews, Puerto Ricans, Europeans, Arabs, white Americans and other racial and ethnic categories.

It must be pointed out that carrying the trait does not mean that one has the disease. Sickle cell anemia is an hereditary blood disease wherein the red blood cells, ordinarily doughnut shaped in form, are sickle in shape. The trait, on the other hand, represents merely a tendency and not the disease. Persons with sickle cell trait have been found to be relatively resistant to malaria. Neither type of sickle cell is contagious. That is, sickle cell trait or anemia can only be inherited, and genes determine what type of hemoglobin an individual will have. Furthermore, sickle cell anemia is simply one of the types of hereditary diseases which handicap children. While the average life expectancy for persons with sickle cell anemia has been found to be less than that for the general population, persons with the disease have been known to live past sixty years of age.

Miss Wilkinson surmissed that because of minimal opportunity to meet basic survival needs, politically and economically powerless racial minorities, in general, have a shorter life span than persons of Euro-American descent.

Miss Wilkinson, concluded that, "If it is assumed that both parents, for example, have sickle cell trait, it is possible to predict the probability of a child being born with sickle cell trait or sickle cell anemia. Each time a child is born when both parents have the trait, there is a $\frac{1}{4}$ probability that the child will be normal. In other words, there is a 25 per cent chance that the child will have neither the trait nor the disease."

Because of the current interest in sickle cell anemia and its affects on Black Americans, there is a need for a work of this nature. Therefore this bibliography should be useful for those that want to know more about this disease or at least traits of it. This work is by no means exhaustive or comprehensive, it is what its title indicates, "Sickle Cell Anemia: A Preliminary Survey."

Obviously, any work of this endeavor encompassed the assistance of many people and many hours. Therefore, it would be nearly impossible to name all persons that assisted in this monumental work, however, I must express special acknowledgement to the following: The Ohio State University Library, and the secretaries, Penny Martin, Judie Strain, Yolanda Robinson, and Sylvia Noel of the Department of Black Studies at The Ohio State University. Without their assistance this work would not have been completed. I take full responsibility, however, for all errors. I also welcome any corrections of errors or omissions.

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THE NATIONAL SICKLE CELL DISEASE PROGRAM*

1. Background and History

Sickle cell anemia, first described in this country in 1910 by Dr. James B. Herrick, is a hereditary blood disorder characterized by the presence of a chronic anemia, jaundice, recurrent bouts of pain called "crises," occasional growth retardation, an increased susceptibility to certain infections, a decreased physical capability, and occasionally a shortened life span. This blood disorder occurs as a result of the presence of genes for sickle cell hemoglobin inherited from both parents. The incidence of sickle cell anemia in Blacks in the United States is approximately one in six hundred. Some 50,000 or more Blacks are thus affected by sickle cell anemia in the United States.

Sickle cell trait is a healthy state wherein one carries the gene for both sickle hemoglobin and normal hemoglobin. Rarely are there problems associated with sickle cell trait and for the most part individuals with sickle cell trait seldom, if ever, know they carry the sickle gene until tested. The incidence of sickle cell trait is approximately one in every ten Blacks in this country and numbers approximately two million individuals.

Despite the fact the disorder was first described in 1910, research and service activities in this problem did not receive adequate attention over the years. In February 1971, in his Health Message, the President indicated that sickle cell anemia is a national health problem and as such included in his budget an additional five million dollars for research and service in this disorder. This amount was later increased to an overall total of ten million dollars in FY 72.

The National Sickle Cell Disease Advisory Committee was named by the Secretary, Department of Health, Education and Welfare, and subsequently held its first meeting in August 1971. Through the recommendations of this Committee the National Program was established and presently consists of several components.

2. Components of the National Sickle Cell Disease Program

A. Sickle Cell Disease Centers

The purpose of the Sickle Cell Disease Centers is to focus resources, facilities and manpower in a coordinated approach to sickle cell disease. This approach includes a combination of research and service with the intent of bridging the gap between these two disciplines. Programs of the Sickle Cell Disease Centers include basic or fundamental research, clinical research, clinical applications, treatment trails, training and education programs, public education, screening, counseling, rehabilitation, and related activities.

B. Screening and Education Clinics

Screening and Education Clinics were established as demonstration projects to determine the best ways to carry out programs of public awareness, public education, screening, Counseling and patient referral. The intent of these programs is that of obtaining data to find out how best to carry out these program components in a variety of environments and under certain conditions.

C. Mission Oriented Research and Development Program

Under the Mission Oriented Research and Development Program, targeted research is carried out by groups of investigators to obtain answers to problems in sickle cell anemia through the contract and through collaborative efforts answers are sought.

D. Research Project Grants

Research carried out under the traditional grant mechanism falls under this category and differs from the above mission oriented program in that the investigator initiates the research problem and requests support for same.

E. Information Program

The need for factual information relative to sickle cell anemia resulted in the establishment of program to collect and distribute factual information that can be clearly understood by the public. To accomplish this, a national clearinghouse for information of sickle cell disease is being established.

F. Training and Education Program

The purpose of this component of the Program is to train and educate medical and paraprofessional personnel and others about the problem of sickle cell anemia such that they may in turn deliver the same information to their local communities.

Individuals or organizations interested in information or applications for any of the above program components may write directly to:

Sickle Cell Disease Branch
National Heart and Lung Institute
National Institutes of Health
Room 5A 03, Building 31
Bethesda, Maryland, 20014

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*Negro History Bulletin, November 1973, p. 157.

Public Law 92-294
92nd Congress, S.2676 - May 16, 1972

AN ACT

To amend the Public Health Service Act to provide for the control of sickle cell anemia.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

SECTION 1. This Act shall be cited as the "National Sickle Cell Anemia Control Act."

FINDINGS AND DECLARATION OF PURPOSE

Sec. 2 (a) The Congress finds and declares -

1. that sickle cell anemia is a debilitating inheritable disease that afflicts approximately two million American citizens and has been largely neglected;

2. that the disease is a deadly and tragic burden which is likely to strike one-fourth of the children born to parents who both bear the sickle cell trait;

3. that efforts to prevent sickle cell anemia must be directed toward increased research in the cause and treatment of the disease, and the education, screening, and counseling of carriers of the sickle cell trait;

4. that simple and inexpensive screening tests have been devised which will identify those who have the disease or carry the trait;

5. that programs to control sickle cell anemia must be based entirely upon the voluntary cooperation of the individuals involved; and

6. that the attainment of better methods of control, diagnosis, and treatment of sickle cell anemia deserves the highest priority.

(b) In order to preserve and protect the health and welfare of all citizens, it is the purpose of this Act to establish a national program for the diagnosis, control, and treatment of, and research in, sickle cell anemia.

AMENDMENTS TO PUBLIC HEALTH SERVICE ACT

Sec. 3 (a) Section 1 of the Public Health Service Act is amended by striking out "titles I to X" and inserting in lieu thereof "titles I to XI."

(b) The Act of July 1, 1944 (58 Stat. 682), as amended, is amended by renumbering title XI (as in effect prior to the enactment of this Act) as title XII, and by renumbering sections 1101 through 1114 (as in effect prior to the enactment of this Act), and references thereto, as sections 1201 through 1214, respectively.

(c) The Public Health Service Act is further amended by adding after title X the following new title:

"TITLE XI - SICKLE CELL ANEMIA PROGRAM"

"Sickle Cell Anemia Screening and Counseling Programs and Information and Education Programs"

"Sec. 1101 (a) (1) The Secretary may make grants to public and nonprofit private entities, and may enter into contracts with public and private entities, for projects for the establishment and operation of voluntary sickle cell anemia screening and counseling programs, primarily through other existing health programs.

"(2) The Secretary shall carry out a program to develop information and educational materials relating to sickle cell anemia and to disseminate such information and materials to persons providing health care and to the public generally. The Secretary may carry out such program through grants to public and nonprofit private entities or contracts with public and private entities and individuals.

"(3) In making any grant or contract under this title, the Secretary shall (1) take into account the number of persons to be served by the program supported by such grant or contract and the extent to which rapid and effective use will be made of funds under the grant or contract; and (2) give priority to programs operating in areas which the Secretary determines have the greatest number of persons in need of the services provided under such programs.

"(b) For the purpose of making payment pursuant to grants and contracts under this section, there are authorized to be appropriated $20,000,000 for the fiscal year ending June 30, 1973, $30,000,000 for the fiscal year ending June 30, 1974, and $35,000,000 for the fiscal year ending June 30, 1975.

"PROJECT GRANTS AND CONTRACTS"

"Sec. 1102 (a) The Secretary may make grants to public and nonprofit private entities, and may enter into contracts with public and private entities and individuals, for projects for (1) research and research training in the diagnosis, treatment, and control of sickle cell anemia, (2) the development of programs to educate the public regarding the nature and inheritance of the sickle cell trait and sickle cell anemia, and (3) the development of sickle cell anemia counseling and testing programs and other programs for diagnosis, control, and treatment of sickle cell anemia.

"(b) For the purpose of making payments pursuant to grants and contracts under this section, there are authorized to be appropriated $5,000,000 for the fiscal year ending June 30, 1973, $10,000,000 for the fiscal year ending June 30, 1974, and $15,000,000 for the fiscal year ending June 30, 1975.

"VOLUNTARY PARTICIPATION"

"Sec. 1103. The participation by any individual in any program or portion thereof under this title shall be wholly voluntary and shall not be a prerequisite to eligibility for or receipt of any other service or assistance from, or to participation in, any other program.

"APPLICATIONS; ADMINISTRATION OF GRANT AND CONTRACT PROGRAMS"

"Sec. 1104 (a) A grant under this title may be made upon application to the Secretary at such time, in such manner, containing and accompanied by such information, as the Secretary deems necessary. Each applicant shall -

"(1) provide that the programs and activities for which assistance under this title is sought will be administered by or under the supervision of the applicant;

"(2) provide for strict confidentiality of all test results, medical records, and other information regarding screening, counseling, or treatment of any person treated, except for (A) such information as the patient (or his guardian) consents to be released; or (B) statistical data compiled without reference to the identity of any such patient;

"(3) provide for appropriate community representation in the development and operation of any program funded by a grant under this title;

"(4) in the case of an application for a grant under section 1101(a)(1), provide assurances satisfactory to the Secretary that (A) the screening and counseling services to be provided under the program for which the application is made will be directed first to those persons who are entering their child-producing years, and secondly to children under the age of 7, and (B) appropriate arrangements have been made to provide counseling to persons found to have sickle cell anemia or the sickle cell trait;

"(5) set forth such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement of and accounting for Federal funds paid to the applicant under this title; and

"(6) provide for making such reports in such form and containing such information as the Secretary may reasonably require.

"(b) In making any grant or contract under this title, the Secretary shall (1) take into account the number of persons to be served by the program supported by such grant or contract and the extent to which rapid and effective use will be made of funds under the grant or contract; and (2) give priority to programs operating in areas which the Secretary determines have the greatest number of persons in need of the services provided under such programs.

"PUBLIC HEALTH SERVICE FACILITIES"

"Sec. 1105. The Secretary shall establish a program within the Public Health Service to provide for voluntary sickle cell anemia screening, counseling, and treatment. Such program shall be made available through facilities of the Public Health Service to any person requesting screening, counseling, or treatment, and shall include appropriate publicity of the availability and voluntary nature of such programs.

"REPORTS"

"Sec. 1106. (a) The Secretary shall prepare and submit to the President for transmittal to the Congress on or before April 1 of each year a comprehensive report on the administration of this title.

"(b) The report required by this section shall contain such recommendations for additional legislation as the Secretary deems necessary."

Approved May 16, 1972.

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* Many of these books have excellent bibliographies.

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